

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation



May 2016

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FEEDBACK



Full Speed Ahead

Sometimes in life, if we are lucky enough, fate or God leads us into a special relationship with someone we need but aren't looking for. That's what happened to me when I reached out, not knowing it, in the middle of the night, only a few weeks following my unexpected laryngectomy. The hand that so sweetly touched mine, was that of Pat Wertz Sanders. Friends, family, my sweet wife Julie, and my own mother and dad, all cared about me and I knew that. Some people close to me could not quite handle what I had just experienced as they were as shocked and terrified as I was. Hard as they may have tried, they couldn't possibly understand how I felt and where I was mentally. I needed a dear, new, friend that could not only identify with me, but read my mind if necessary.

As I recovered in my recliner, dozing in and out much of the day, I often found myself awake at night and would spend the time attempting to learn about this new life. There was so much I did not know and I was unsure where to turn. I struggled to remember the name of an online group I'd heard about, thinking maybe I needed it after all. Somehow I came up with WebWhispers, which lead me to some information about a "voice institute". Flat broke and jobless, I explored the information I could find about it. It was mid-May and I had to hurry so I went to the top. I sent an email to the President of WebWhispers thinking at least this person would be irritated enough to refer me to the right people and information and get me out of her hair. Little did I know! In my inquiry, I noted that I wanted to help other people. She picked up on that and latched onto me, giving me hope and a sense of purpose I had not expected or even dreamed I would ever have again. Because of Pat, I was able to go the Voice Institute in Buffalo and the rest, as they say, is history.

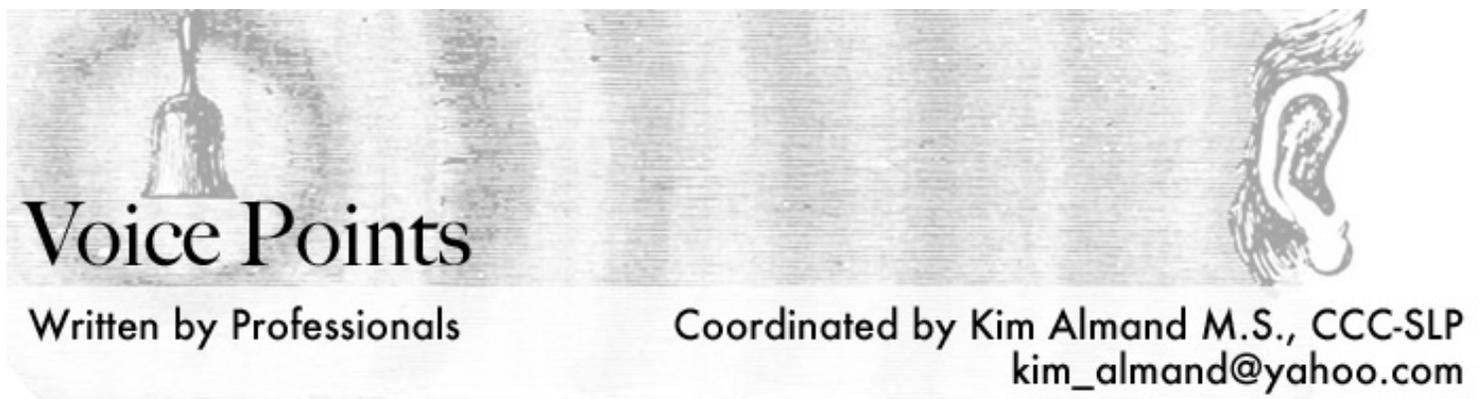
We chatted some and within a couple of weeks, I received an email from Pat with the greeting "Tom, my dear new friend". That relationship I wasn't looking for and did not know I needed was here. When I first saw Pat in person, I was greeted with a bright-eyed, smiling face of passion, empathy, and sincerity. As I began to do things for WebWhispers, she became more a part of my life. As I journeyed through the first couple of years of larydom, she was right there. The more I struggled with issues, the more encouraging and supportive she became.

Without us even knowing it, Pat operated with a concept I learned best upon becoming a Navy Chief, that of training your replacements. Pat has done that for many years and has trained us exceptionally well. The result is an experienced, devoted Board of Directors and other highly skilled people on our leadership team who work tirelessly to keep our organization up and running. As Interim President, I can assure each of you that Pat is not gone from us; she left a piece of herself within each and every one of us. As we collectively

apply those pieces, we will continue to meet the mission of WebWhispers, sharing support worldwide for survivors of laryngeal cancer and other forms of throat cancer. Pat would have it no other way, and as we strive to honor her legacy, I say “full speed ahead”!
Only a couple of weeks ago, I held her hand in both of mine and said “I love you”. With a little of that same sweet smile, she responded “I know - I love you, too”.

Good friends never say goodbye, only “farewell, until we meet again”.

*Enjoy,
Tom Whitworth
WebWhispers President*



Pat's contributions to WebWhispers

Pat Sanders was beloved by her family and many friends and members of the laryngectomy community, and will be deeply missed. Her contributions to WebWhispers were numerous. A prolific writer, Pat contributed each month to Whispers on the Web. She also wrote and compiled hundreds of pages and links of useful information for the WebWhispers library. Reaching out to laryngectomees and their caregivers on a regular basis through the daily digest, she encouraged them to share their own personal experiences. Pat acknowledged that others learn from these stories and it often “saves pain or gives hope.”

Likewise, Pat sought input from numerous professionals involved in the care of head and neck cancer, including physicians, speech-language pathologists, clinicians and researchers. She was a staunch advocate for professional involvement in WebWhispers through this VoicePoints column. Pat was adamant that in this column, discussion on various levels of the most “basic” issues, the ones that people experienced all the time, was significant for clinicians, advanced laryngectomees, and anyone reading who wanted to know more. When, however, on occasion I expressed doubts about the relevance of the column or the topic for the month, Pat’s answer was straightforward and practical, humble: “Styles vary greatly.....even if someone has written on a subject, it is OK to do it again..... You never know how you might touch someone.” “With new discoveries and longer trials of ways of treating our problems, we need all of the latest we can get.” Pat was relentless in her quest to help people be as well-informed as possible. She spent her time uncovering helpful tips in the WebWhispers archives, reaching out to new contributors for this column and asking about issues that would ultimately lead to new research questions and further discussion among our members.

Pat carried out all these duties with her characteristic quick wit and determination. Her lovely smile and endearing words will be greatly missed. And yet, we know that we have Pat's blessing as we continue on with our work. She was aware that she was leaving WebWhispers in excellent hands with Tom Whitworth as our interim president, along with the rest of the board of directors and leadership team. In keeping with Pat's legacy, we will continue to use VoicePoints as a place to build up our community: to read about latest advances in our field, provide resources to clinicians, teach students, share research; communicate with clinicians, laryngectomees, and caregivers. In so carrying out this work, we aim to give the same hope to each other that our dear Pat offered abundantly to us.



More Than the Sum of Our Parts

I imagine that many of you felt as I did when we learned the seriousness of Pat's condition and although saddened were not surprised to hear of her passing. It was like losing an elderly parent. You know they have lived long and well and that death comes to us all eventually but it leaves you feeling a little lost and suddenly painfully aware of that space they occupied in your life for so long. I am not sure Pat would appreciate being called elderly but at 86, nearly 87, that's pretty much true! While it has some negative connotations in our modern youth-oriented society, elder has been a term of respect for far longer. And she was our elder stateswoman for sure.

I first met Pat in person in Galveston TX , December 2004 as we arrived for the Panama Canal cruise. I had only recently joined WebWhispers although my journey with throat cancer had begun over 3 years earlier. I was just beginning to feel like I had my life back and my mother, who is only a few years older than Pat, and I were taking this cruise in celebration. Pat came to our room, introduced herself and immediately started coaching me on using my Servox, tying my scarf and generally assuming control and taking me under her wing - in other words, typical Pat. It was wonderful and both my mom and I felt relieved to be around so many knowledgeable folks who truly understood this new lary life. Later that week I rode with Pat out to Mayan ruins and she discovered I "did some writing" and immediately asked if I would be interested in writing for the WW newsletter. I was thrilled and jumped at the chance. She had never even read a word from me but she took a chance and I will be forever grateful that she did. I say jokingly I was shanghaied for WW on that cruise.

When we got back home I sent her a copy of the journal that I had been writing since my initial diagnosis and that same day she offered me an extraordinary opportunity to re-invent myself in this strange new world. Between Friends debuted March 2005 and with few exceptions it has managed to appear here every month since. I have said many times I had to lose my voice in order to find it.

As it turns out, I am not the only one writing here these days who feels the same way. Both Len Hynds and Noirin Sheahan have similar experiences with writing in general and WW in particular and I am sure there are others.

Pat found her life's calling in WW. With guts, determination and persistence she shaped WW into the wonderful organization we know today. To her lasting credit she realized that her vision alone was not enough to carry WW forward. She understood that it must become greater than the sum of its parts. WW works as well as it does because of ALL its members and the vast resources they encompass. Every single member can contribute and it is the sum total of those contributions that keep WW functioning as folks ask and answer questions or offer advice on the daily list, write columns here and offer hints and suggestions and referrals that go into the library – all the wealth of information that is WW today.

Pat's ultimate legacy is one of inclusion – that each and every one of us is valuable and together we are stronger and better. WebWhispers is not dependent on any one of us to continue and while we deeply mourn each loss we have been made better because of each and every one's presence. She left us with a great gift and for that she will always be remembered and loved.



The regular Speaking Out questions and answers were replaced by the below remembrances of Pat Sanders.

Pat Sanders joined our hole in the neck family on March 31, 1995. Ironically her new normal began on my birth date and it was the beginning of a long friendship and a lasting legacy on her part.

I first "met" Pat sometime in 1996 but it's just been too long ago to put an exact date on it. Our first encounter took place on the CompuServe Forum which I hosted for laryngectomees on their Head & Neck Cancer

Forum, while Len Librizzi (former WW webmaster and editor) did the same on AOL's forum. That's how we both met Pat. Boy did she have a lot questions back then, unlike later when more often than not it was her that had the answers, and if not tried to find them.

Back then Pat was just learning to use the computer her son had bought her even though she couldn't even type. But, that was her first means of communicating while she learned to use her electro larynx. A Servox I believe but after all these years I could be wrong on that part. For reasons that I don't recall she had been waiting quite a while for her puncture so she could be fitted with a prosthesis, and she told me that she was going to use the Bivona Colorado, an early combination of a trach tube and prosthesis combined. I advised her that most people that tried that method failed for various reasons mostly related to needing an exact fit and alignment with the puncture, but Pat being Pat was determined to try it anyway. Well it didn't work and they are no longer in business, but Pat was just getting started.

Not long after that Pat started her "Kirkland Headlines" newsletter, and we both joined a new group started by some guy named Dutch Helms. That newsletter became one of my favorites and I looked forward to it every month. When I asked for permission to reprint some of her articles in my newsletter (Look Who's Talking) she was actually surprised that someone would actually want to do that. But, as many of us know after reading her for the past 20 years she was an amazing writer and an avid researcher.

For years I tried to get Pat to join the International Association of Laryngectomees board but she always declined and wouldn't even attend a meeting. She was perfectly happy helping with her local group (which didn't belong to IAL) and posting comments on Dutch's site. Then three things happened that profoundly changed the face of laryngectomee support as we knew it.

The first was to convince Dutch to give up his format where everyone sent him an email and then he forwarded it to his members, and switch to the current listserv system we now use. That generated a lot more new members, speeded everything up, and made it easier to communicate.

The second thing was to finally accept my invitation, and the offer of a scholarship, to attend the 1999 IAL Voice Institute in Reno. As Pat has written before that was like an epiphany to her as far as laryngectomee knowledge and the quest for more goes. Up till then she was a good, occasional contributor to the discussion. But from that point on she never stopped talking or writing and she was fantastic at it.

The third and probably the longest enduring contribution she made was her guidance and leadership in transforming Dutch's group into the organization that became WebWhispers. She was instrumental in forming the board, bylaws, procedures, revamping the website, and generating the best damn laryngectomee newsletter in the world.

Pat will be missed, but rather than mourn her loss I hope we all rejoice in the love, comfort, and joy she brought to our world. Honor her memory by continuing her legacy of paying it forward to all those that need our support. That will make her smile.

Below are a few more profound and heartfelt tributes to that memory.

~Jack Henslee

Looking through the past newsletters I was overwhelmed at all the contributions that Pat Sanders made, even though I saw them day after day. She was such a special person and getting to know her was a privilege. She touched my life so much, as she did countless others. She will be in my heart and thought

forever. Losing someone you care about is hard but I learned from the loss of my parents that the thoughts turn into the good memories over time. I think of my parents every day, as I will of Pat. If I smile for no reason it is because something reminded me of a special time or memory. Some people achieve fame but the best legacy is for a person to be remembered and loved for the good she has done, and Pat has done that to a high degree.

~Ron Mattoon

I met Pat as I was volunteering as a moderator for WebWhispers. She asked me if I was interested in helping with the accounting side of the organization by writing acknowledgment letters for donations to WebWhispers. I told her I would be glad to do that, so our friendship was developed as I learned what to put in a letter and what to leave out.

She guided me as a pilot does a ship with a kind, firm hand. I was so appreciative of being able to ask her any question regarding the letters and to receive an answer immediately. . I will miss her guidance, yet I believe she will still guide me with her wonderful ways.

~Marilou Percival
Member Services.

Pat Sanders was my friend. She also happened to be the President of WebWhispers, but primarily she was my friend.

If I needed advice, she was one of the first I would turn to. I valued her opinion and 9 times out of 10 I followed her advice. The few times I didn't, I wished I had.

Pat was a strong leader. She led WebWhispers with a firm hand, staying with founder Dutch Helms wishes. The determining factor for difficult situations was always "What would Dutch do?".

She will be missed, but will live forever in the minds of those that loved her.

~Jim Lauder
Lauder Enterprises

WebWhispers is place where I have made many new friends and perhaps because we share a similar lifestyle we tend to feel a special bond. Unfortunately I have not met many of these new friends in person, but only online.

All too often one of my new special friends passes on to even greater glory and in doing so leaves a hole in my heart. Pat Sanders was one of those special friends, not only to me but to everyone she met. Many of you may only know of her as the President of WW for many years but she was much more than that to all of us whether you knew it or not.

To say she was a human dynamo is an understatement since she would accomplish more in one week than many of us would in a month. She had a special penchant for not just Larys but for all cancer survivors. Her tireless efforts for the WebWhispers community has provided us with a solid base of survivor support including patients and family members. The WebWhispers' library was one of Pat's pet projects and is a

treasure for us to maintain so those who follow us will continue to benefit from it.

Pat will be missed by all of us but I am happy to have known her and even happier to call her a special friend.

Rest in peace, my Friend!

Frank Klett

Much to my luck, Pat and I got to have a few long phone talks and e-mails, and got to know each other personally a little bit. More important though is that very fortunately for the whole laryngectomee community Pat was there at the right place and the right time - and willing and able to stay a while. We'll all be missing her, but she'll be looking down and glad to see that the group she loved so much remains well organized and is carrying on.

Dorothy Lennox
Luminaud, Inc.

Pat Sanders was one of a kind.

An intelligent, decisive, generous and common sense woman with a very warm heart, Pat was the driving force behind the modern day WebWhispers.

Building on Dutch Helms' foundation for WebWhispers, Pat worked tirelessly to help build what would become the largest and most respected self-help organization for laryngectomees. When faced with a particularly challenging decision, she would always ask; "now what would Dutch do?".

With her lovely smile, twinkling eyes and charming personality, I looked up to Pat as the mother hen. A good listener, she genuinely cared about the well-being of others and would go out of her way to help her friends and colleagues.

We've all lost a very dear friend with a heart of gold. She will be greatly missed.

Richard Najarian
Bruce Medical Supply

Pat, as I will always remember her - with a smile and a laugh that would light up the room.



~ Mike Rosenkranz
VP Website Information

When it comes to Pat W. Sanders, I will always wonder how God placed such a big heart and mind into such a tiny body. When I stepped into the WebWhispers scene as a laryngectomee in 2000, it was clear to me that she was already heavily involved behind the scenes assisting Dutch with the many facets of the organization.

I will always admire her for her dedication to WebWhispers and its members. It seems she reached out to all, endlessly and tirelessly. I jokingly asked her on numerous occasions: "Don't you ever sleep?" She would reply with a chuckle and stated that she would catch a nap in the afternoon. I still don't know if she ever slept but I do know for certain that I have evidenced her works throughout all hours of the day and night.

Like countless others, Lisa and I will dearly miss Pat. Often Pat would phone to discuss WebWhispers related matters with me and she would end up in lengthy conversations with Lisa, discussing anything and everything under the sun. Pat was extremely knowledgeable about most anything and everything under the sun. She was the most intelligent person I have ever had the pleasure of meeting and knowing. We did not always agree on matters but could always agree to disagree without any loss of respect on either side. Pat was very giving of herself and her time and very dedicated to serving the lary community in any way possible. She will certainly remain an "icon" for years to come.

Pat will be dearly missed by countless others, including Lisa and myself. She touched our lives and will be forever etched in our memories.

~Michael Csapo
WW BOD

Next month's Speaking Out Question is:

What drove your decision to use the type of speech that you choose. Were the various options explained to you?

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.

Staff of Speaking Out



Saying Farewell to Pat.

Like all of you I was very sad to hear of Pat's death. I was also surprised and a bit shocked. Although I knew she had been seriously ill, I was sure her positive spirit would win through. It is hard to believe that her vibrant being has departed this life and that we can no longer expect her crisp, clear, intelligent input to WebWhispers.

Although I never met Pat in the flesh, I felt as though I knew her well from her column in the newsletter and her contributions to the digest and in the Forum. I can't see her suffering fools gladly! Instead I see her as energetic, practical, determined, good humoured, down-to-earth and very positive. Her range of knowledge was vast – whether it was medication problems, infections, thyroid issues, diet, TEP leaks, hydration, mucous, swallowing difficulties, neck and shoulder stiffness or almost any laryngectomy health issue, Pat had a ready stock of knowledge. And in the wide area of living well with laryngectomy she had so many good suggestions – her tips on swimming come to mind and on making friends with people who stare at us.

She was a great leader for Webwhispers. We are lucky that Tom is willing to take her place in this difficult time; Pat would want WebWhipers to continue and to thrive, so many thanks to Tom for leading the way.

Last October, Pat's column in the newsletter was entitled "Setting some Ashes" and told the story of how she had tackled the thorny issue of what was to become of her body after death. She told it in a light, humorous way which took the edge off the negativity we all feel when speaking of death. It was typically generous of

her to find her way through the unfamiliar vocabulary of “second rights”, “inurnment”, “interment” and “entombment” and make all the necessary decisions and arrangements to have her ashes buried in her parents’ grave.

It’s not an easy thing to think about – our own death. But it is an act of kindness to decide on our funeral arrangements rather than pass that burden on to our nearest and dearest. Typically, Pat went the extra mile and purchased her urn-vault (a sort of coffin for cremated ashes) and signed the contract for opening and closing her mother’s grave. Her no-nonsense spirit dismissed the expense of an urn with: “I think we can find a cigar box!”

Maybe it was as a result of Pat’s column that I started thinking more deeply about what I want to happen at the time of my own death. Burial or cremation? Embalming? What ceremonies do I want at my funeral? And before death, what prayers, ceremonies, music etc. would help me die most peacefully? If I can’t communicate and the doctors say there is no hope of recovery, would I want antibiotics, tube feeding, cardiac resuscitation or other life-saving procedures? Would I prefer that all such attempts to prolong life be withheld so that I can die naturally – as people did before all this technology? Who would I appoint to communicate with the doctors about all this? I had made some quick decisions in this area before my laryngectomy as I was only given a 50:50 chance of getting through the critical few weeks post-op, but hadn’t been able to think with any depth. Thanks to Pat’s article I’ve since found a form called “Thinking Ahead” which you can download and which guides you through all the legal, financial, practical and spiritual issues that come up at the end of life. Along with a group of my friends, we’ve started discussing these questions and making the necessary arrangements. I’m glad to be tackling this business – it’s like I’m valuing myself and my family and friends, not just in life, but also in the challenging business of death and dying.

Perhaps Pat’s last gift to me was to spur me into making these end-of-life decisions. Her first gift was to welcome me so warmly into Webwhispers and invite me to write for the Newsletter. Having to reflect each month on some aspect of life with laryngectomy has proved very valuable in living well with this condition. Writing this column is like finding a post-laryngectomy voice and I will always be grateful to Pat for initiating this.

I’m very grateful also to Pat’s good friend Peggy Byron for taking our cards, and to Pat’s son Scott for setting up the GetWellPat email address and to Tom for keeping us up to date and reminding us to send cards and messages. These give some sense of having been with her till the end. Now that she is gone, there is a natural grief and I find myself wishing I had known her better, sent more emails etc. But clinging to grief and regret won’t help either of us. In my understanding, my job is now to say “Goodbye Pat” and wish her well on her onward journey. Each time I manage a heartfelt ‘goodbye’ it frees up my imagination of where and what and how she is now. So here’s how I found myself imagining her this morning ...



... I'm visiting my friend Finola who lives in Kinvara which is a little town on the south coast of Galway Bay. When we went for a walk on the Burren this morning, I found myself inviting Pat to come along with us. Now I know at least 99% of Pat's spirit is with her dear son Scott, but I was fantasising that some small bit of the remaining 1% had made it across the Atlantic to join us! In my imagination she was really enjoying herself in the vast open spaces and with the sun shining, the sea sparkling and spring flowers starting to appear between the rocks. I was chatting away to her, saying 'thank you', wishing her well in her new life. I took some photos and I'm hoping Donna can include one in the newsletter. If your imagination will stretch this far, think of these as an image of where some part of Pat's spirit may have spent her first weekend in the afterlife!



Why not invite her along when you visit your favourite place? She always loved the annual WebWhispers cruise – maybe she can now cruise among our many and varied paths in life! I know I'm being a bit fantastical, but then again, what do any of us know about the mystery of life and death? She certainly deserves all the love and care we can show her as we each find our ways to say farewell.



Pat's Poem

We speechless people have lost a friend,
when Pat's life of service, came to an end.
A mother to our family wide,
her compassion, she could never hide.

If she could speak to us today,
sadly to say, " I could not stay.
Jesus opened his arms to me
and my youthful spirit, became free. "

" So no longer must you weep,
though I have gone, I'm not asleep.
I'm with you still in every way.
I am, my dears, with you today."

" I am the summer breeze that blows ,
the wonder of those winter snows,
each sparkling star you see at night,
I am, my dears, within your sight."

" I am the sunlight on ripened grain,
I am the gentle autumn rain.
I am each golden grain of sand,
I am the one who holds your hand."

"So my dears, no longer cry,
though not here, I did not die."



The following article appeared here in September , 2007. We did manage to surprise Pat and thought it appropriate to reprint here in tribute ~

Dear Webbies,

At the IAL meeting in Burlington, this past July, Barb Stratton approached me with a proposal for a bit of subterfuge! She wanted to write a tribute to Pat's contributions to WW but she felt that if she submitted it through the normal channels, Pat would either edit it to smithereens or just not print it at all. She asked if she sent it to me, could we circumvent Hawkeye Sanders? I told her I was sure I could enlist the help of Len Librizzi and thus this plot was hatched. To my knowledge, we succeeded and Pat has only read this now... as you all do.

I think a little background on Barb might be helpful. She was one of several alternate moderators Dutch trained prior to an IAL meeting several years ago, so when he and Pat were both out of town, they could breathe easier.

As WW expanded, the Moderating job was an easy one for him to let go of; that way he could attend to managing the list and everything else he did. The Forum was another branch that could be delegated and he chose Mike Rosenkranz for that job. Then when doctors' visits and hospital stays began to eat into his time, he concentrated on teaching both Mike Csapo and Barb the list manager duties, as well as moderating. For a while they swapped jobs each month back and forth, and after several months realized they each had a preference - Barb's for moderating and Mike for list managing. And under Pat's guidance, things just kind of fell into place as Dutch became less accessible. The rest of the recruiting Pat did pretty much herself, seeking their input now and then on responsibilities. Despite her daily involvement, Barb keeps a low profile. She is not a lary; her husband has been since 1999, and Barb became involved with WW in 2000 as a caregiver. I think her continuing involvement, even in the face of her own medical issues, just points out the critical role caregivers play in the ongoing success of WW and the lary community.

What she writes about Pat is certainly true and Len and I were only too glad to be a part of the "Stealth Tribute"

Donna McGary

A year ago last spring, Pat, clearly in tears, called me and said, "I am afraid Dutch might not make it." It was hard to believe - even after seeing the pictures he posted of his angry looking fistula - that our founder and mentor would not be around forever. What Pat did know for sure was that whatever measures his doctors pursued, he wouldn't be able to maintain his 24/7 running of WebWhispers during his treatment and recovery for an unknown amount of time.

It was with kid-glove finesse she set about encouraging him to turn over bits of knowledge and advice about making our website accessible to more than a single individual for updates. Until then, if something needed to be changed, it was Dutch alone that could trigger the correction. Pat recognized that it would take many hands to fill

his role, and we needed his help along the way to get a "new" system set up with his blessing. The goal was to make it as identical as possible, but maneuverable without him. And not sound like it was a "before you die" thing.

She gathered a crew - some already active in the running of WW, and some new and talented in Internet software applications who could say you can't do that, but we can do this and reach the same goal. She sent out applications for grants, knowing whatever we did was going to be expensive, and she recruited and made optimum use of volunteers to lighten the new financial burden.

It will be a year next month since the new site clicked into place. We made it over all the speed bumps and unexpected curves that were thrown, and have not only held together our wonderful group, but increased our roster by over 550. The management of new member information and updates is accurate and speedy. Archived lary-oriented wisdom from members and professionals is easy to access from the website, as is member information. The Forum has become more active than ever. And it isn't any easier to slip something unacceptable onto the List than it was when Dutch was Moderator!

This may be the first ever article in Whispers on the Web to bypass Pat's compulsive red-pencil edit, but we knew it would never fly if she saw it first. We just wanted all members to know that she deserves a lot of credit for all that we still are today, and say thanks for your foresight Pat! Dutch would be proud to see how his baby is thriving with only his dreams, not his hands at the helm.

Barb Stratton

WebWhispers is an Internet based support group. Please check our [home page](#) for information about the WebWhispers group, our email lists, membership, or officers.

For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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